

LEGISLATURE OF NEBRASKA  
ONE HUNDRED FOURTH LEGISLATURE  
SECOND SESSION

**LEGISLATIVE BILL 891**

Introduced by Brasch, 16; Baker, 30; Bloomfield, 17; Coash, 27; Cook, 13;  
Craighead, 6; Crawford, 45; Davis, 43; Ebke, 32; Fox, 7;  
Friesen, 34; Garrett, 3; Gloor, 35; Groene, 42; Haar, 21;  
Hansen, 26; Harr, 8; Hilkemann, 4; Howard, 9; Hughes, 44;  
Johnson, 23; Kintner, 2; Kolowski, 31; Kolterman, 24;  
Krist, 10; Kuehn, 38; Larson, 40; Lindstrom, 18;  
McCollister, 20; Mello, 5; Morfeld, 46; Murante, 49;  
Pansing Brooks, 28; Riepe, 12; Scheer, 19; Schilz, 47;  
Schnoor, 15; Schumacher, 22; Seiler, 33; Smith, 14;  
Stinner, 48; Sullivan, 41; Watermeier, 1; Williams, 36.

Read first time January 11, 2016

Committee: Health and Human Services

- 1 A BILL FOR AN ACT relating to public health and welfare; to adopt the
- 2 Down Syndrome Diagnosis Information and Support Act.
- 3 Be it enacted by the people of the State of Nebraska,

1           Section 1. Sections 1 to 4 of this act shall be known and may be  
2 cited as the Down Syndrome Diagnosis Information and Support Act.

3           Sec. 2. For purposes of the Down Syndrome Diagnosis Information and  
4 Support Act:

5           (1) Department means the Division of Public Health of the Department  
6 of Health and Human Services;

7           (2) Down syndrome means a chromosomal condition caused by cell  
8 division that results in the presence of an extra whole or partial copy  
9 of chromosome 21;

10          (3) Down syndrome organization means any national, state, or local  
11 nonprofit organization primarily involved in providing advocacy, support,  
12 and education to individuals with Down syndrome and their parents;

13          (4) Health care facility has the same meaning as in section 71-413;

14          (5) Health care practitioner means any person who is credentialed  
15 under the Uniform Credentialing Act to provide health or medical care in  
16 the ordinary course of business or practice of a profession, including a  
17 genetic counselor, who provides prenatal or postnatal care, and who  
18 administers or requests administration of a screening or diagnostic test  
19 that detects Down syndrome;

20          (6) Parents means (a) expectant parents of a child who receives a  
21 prenatal screening or diagnostic test result for Down syndrome, (b)  
22 parents of a child postnatally diagnosed with Down syndrome, and (c) a  
23 legal guardian of a child diagnosed with Down syndrome;

24          (7) Test means any prenatal or postnatal screening or diagnostic  
25 test which indicates the high likelihood or definite presence of Down  
26 syndrome.

27          Sec. 3. A health care facility or health care practitioner, upon  
28 receipt of a test indicating a high likelihood or definite presence of  
29 Down syndrome, shall deliver to the parents the information support sheet  
30 provided by the department under section 4 of this act.

31          Sec. 4. (1) The department shall make the following information

1 available:

2 (a) Up-to-date information about Down syndrome that has been  
3 reviewed by medical experts and Down syndrome organizations. The  
4 information shall be provided in a written format and shall include the  
5 following:

6 (i) A clinical course description, including possible physical,  
7 developmental, educational, and psychosocial outcomes;

8 (ii) Treatment and therapy options; and

9 (iii) Life expectancy; and

10 (b) Contact information for Down syndrome organizations that are  
11 nonprofit and that provide information and support services for parents,  
12 including first-call programs and information hotlines specific to Down  
13 syndrome, resource centers or clearinghouses, and other education and  
14 support programs for Down syndrome.

15 (2) The department shall post the information required in subsection  
16 (1) of this section on its web site and shall include an information  
17 support sheet to be delivered by health care facilities and health care  
18 practitioners to parents as prescribed in section 3 of this act.

19 (3) The department shall ensure that the information required in  
20 subsection (1) of this section is culturally and linguistically  
21 appropriate for parents.

22 (4) A Down syndrome organization may request that the department  
23 include the organization's informational material and contact information  
24 on the web site. The department may add the information to the web site  
25 upon request.